

Epilepsy Care Group Singapore Awareness Association: More patients cope with diagnosis of epilepsy



As he was growing up, Paul Shaffer sometimes froze in his tracks and felt like he was walking away from his body.

He did not tell anyone about the sensation, which usually passed quickly: “Who would believe me?”

It was not until he was in his 20s and convulsions knocked him out of his chair at work that a doctor told him he had epilepsy and he was having seizures. Still Shaffer, now 54, did not do anything about it until years later when he crashed his car and his wife insisted on a **proper assessment and treatment**.

It's not uncommon for epilepsy to go undiagnosed and untreated for years. Doctors don't always recognize it or don't want to label the condition. Because it can be stigmatized, patients don't always accept the diagnosis, even as the condition wreaks havoc on their lives.

But researchers are discovering that epilepsy affects far more people than ever thought. About 3.4 million Americans, including about 59,900 Marylanders, had epilepsy in 2015 - a 25 percent jump in about five years, according to a report released this month by the U.S. Centers for Disease Control and Prevention.

While the CDC could not fully explain the rise in cases, attributing it partly to population growth, officials at the Epilepsy Foundation and others say there is no doubt that the numbers reflect a far more thorough accounting of people with the condition.

“We don’t have the equivalence of a pregnancy test, a yes or no,” said Dr. Jennifer Hopp, a neurologist at the University of Maryland Medical Center who leads the center where Shaffer is being treated. “There is a comprehensive evaluation that needs to be done. And every patient is a little different.”

Epilepsy is a brain disorder that causes any kind of seizure, from convulsions to staring to confused behavior. The condition can stem from strokes, head injuries, infections or genetic mutations, and is diagnosed when someone has two unprovoked seizures or one seizure but is likely to have more.

Seizures often frighten sufferers and people who witness them, perpetuating the stigma, said Patricia Osborne Shafer, the Epilepsy Foundation’s senior director of health information and resources and epilepsy clinical nurse specialist in Beth Israel Deaconess Medical Center’s Comprehensive Epilepsy Center in Boston.

“People fear the word epilepsy,” said Shafer, who did not know until college that she had the condition because doctors only told her she had a seizure disorder, perhaps cutting her off from resources that were available. “This feeds into why people may not know or haven’t been told they have it.”